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ABSTRACT

Provided are materials from a workshop on parental attitudes toward their handicapped children and professionals' attitudes toward parents. Listed are four workshop objectives: to develop an existential view of parental attitudes, to identify the five frequently observed parent attitudes, to provide experience in working through four parental attitudes (acceptance, denial reaction, overprotectiveness, and disguised and overt rejection) to facilitate parental involvement, and to develop a summary of learnings. Included are information on a theoretical framework of parental attitudes (J. Lapides); five monologues (J. Lapides) which illustrate the five types of identified attitudes; a 15-entry bibliography; a paper on planning a parent program (D. Lillie); a list of areas where psychologists fail with parents (R. Blanco); a table on a systematic approach to parent involvement (M. Karnes and R. Zehrback); and a list of 10 considerations parents of retarded individuals want from a clinic (M. Skelton). (SB)

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HELPING PARENTS TO HELP CHILDREN
An Existential View of Parental Attitudes Toward Their Handicapped Children, and of Professionals Toward Them

Part I: A Theoretical Framework

Presented as a workshop to the
Annual Conference of the
Council for Exceptional Children

April 6, 1976
Chicago, Illinois

Presented by
Joseph Lapides, EdS
Director of Mental Health Services
Office of Child Development
Office of Human Development
Department of Health, Education and Welfare

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HELPING PARENTS TO HELP CHILDREN

April 6, 1976
Annual Conference of the Council for Exceptional Children
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Director of Mental Health Services
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OBJECTIVES

1. Develop an existential view of parental attitudes toward their handicapped children, and of professionals toward them

2. Based on this theoretical framework, identify five freqquently observed parent attitudes

3. Experience in working through four parental attitudes which will facilitate increased parent involvement in working with their handicapped children

4. Develop a summary of learnings

AGENDA

Introductions and group formations	3:30 p.m. - 3:50 p.m.
Presentation of theoretical framework (lecture)	3:50 p.m. - 4:05 p.m.
Identification of Parental Attitudes (exercise)	4:05 p.m. - 4:20 p.m.
Role Plays (experiential)	4:20 p.m. - 4:50 p.m.
Summary (group reports)	4:50 p.m. - 5:00 p.m.

HELPING PARENTS TO HELP CHILDREN
An Existential View of Parental Attitudes Toward Their Handicapped Children, and of Professionals Toward Them

by Joseph Lapides, EdS
Director of Mental Health Services
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The late Eric Berne, California psychiatrist who developed the concepts of transactional analysis, formulated what he called "existential positions" that each person develops as the product of "a million different moments, a thousand states of mind, a hundred adventures and usually two different parents." (Berne, 1971)

Such positions, or attitudes, help to explain parental views toward the special child and toward the special education worker. Further, these positions give insight to the worker in how to cope, and to build on, such attitudes.

As the result of early experiences, which involve attributions given to them by their own parents, their messages on how to behave, the orders which the parents gave, the recognition they received and the behavior and feelings which were ignored and/or put down -- all these experiential factors were transalated by the parents when they were children into a self-concept that was applied personally and then extended to others.

The existential position is explained by two continuums. The first extends from OKness (high sense of acceptance) to NOT OKness (low sense of

acceptance). The second continuum travels from "I" (my view of myself) to "Thou" (my view of others).

Thus, the accepting, or "healthy" position is "I'm OK, You're OK." Here, acceptance of self and of others is high and is based on reality, rather than a euphoric, Pollyanna view of the world.

A hostile, "holier-than-thou" position becomes "I'm OK, You're NOT OK." I view myself as good and wise and if I experience any internal low self-concept, I project it onto others.

A third position, "I'm NOT OK, You're OK," reflects a depressive, self-abasing stance. I am not worthy, so I look to you and others for guidance and direction.

The final position is one of futility, hopelessness and despaire, or "I'm NOT OK, and You're NOT OK" either. These four basic positions were popularized by Thomas Harris, M.D., in his book, "I'm OK -- You're OK."

Three-Handed Positions

Berne (1971) later expanded this concept and added a third party to one's sense of acceptance, e.g., "I'm OK, You're OK, They're OK."

It is in these "three-handed" positions that Berne's work takes on meaning in analyzing the attitudes of parents toward their handicapped, or gifted, children, and toward those who serve them. (Inversely, the same exploration can be made of the special education worker's view toward special children and their parents.) View attitudes from this perspective, eight positions unfold:

1. I'm OK, You're OK, They're OK
2. I'm OK, You're OK, They're NOT OK
3. I'm OK, You're NOT OK, They're OK
4. I'm OK, You're NOT OK, They're NOT OK
5. I'm NOT OK, You're OK, They're OK
6. I'm NOT OK, You're OK, They're NOT OK
7. I'm NOT OK, You're NOT OK, They're OK
8. I'm NOT OK, You're NOT OK, They're NOT OK

In developing these eight positions below, the position is stated first, with a one- or two-word description following in parenthesis. Two columns then follow, one for a description of parental attitudes, and the other for a description of the worker attitudes. In the "Parent" column, the "I" represents the parents view of themselves, the "You" refers to the parents' feelings about their child, and "They" represents the parental stance toward the special education worker. In the "worker" column, "I" refers to the workers view of self, "You" represents the worker's view of the child, and "They" reflects the worker's attitudes toward the parents.

1. <u>I'm OK, You're OK, They're OK</u> (Democratic Stance)

Parental Attitude:	Workers' Attitude:
While the parents may have experienced a variety of feelings about their child upon discovering the handicap (ranging from disbelief to sadness to resentment and so on), the parents have come to accept the fact of their situation and now wish to get on with facilitating all possible avenues of treatment. They view the special education worker as someone who can be of assistance and respect her/his qualifications but do not sit in awe of these abilities.	The worker recognizes the extent of the handicap and views the disabilities as a place from which to begin corrective action rather than as simply a limiting force. The worker is aware that her/his diagnosis may be subject to other interpretation, but does not find this threatening. Her/his view of parents is one of a partnership, with both providing essential resources for the child.

2. I'm OK, You're OK, They're NOT OK (Demogogue)

Parental attitude:	Workers' Attitude:
The parents here find fault with nearly everything the worker or institution attempts, and will frequently "shop around" for specialists or move their child from clinic to clinc. They sometimes say things like: "There is nothing wrong with my child that a good clinic can't fix." The trouble is, there are no good clinics in the parents' view. Often the parents deny the child's handicap.	In this stance, the worker believes in himself, in the child, but blames the parents for the major difficulties the child is facing. He may say: "Nothing wrong with that child that a new set of parents couldn't fix." Rather than view the parents as potential helpers in working with the child, he is likely to insist on institutionalization "for the child's good."

3. I'm OK, You're NOT OK, They're OK (Malcontent)

Parental Attitude:	Workers' Attitude:
Most likely to occur where the child has either a learning disability or possesses an emotional disturbance. The parents view themselves and the professional as hard working and probably long suffering. "If only the child would try harder . . ." Sometimes the OKness of "They" includes other siblings, which comes across like "Why can't you be like your brother?" This position may also be manifested by overprotectiveness toward the child, rather than as open hostility.	Less likely to occur among the special education professional, but may be present among untrained teachers or among inexperienced caretakers. This person may say to the parents: "I know you feel, she's so frustrating." To the child: "Now, your parents have sacrificed so much to have you here, so you had best follow our rules. You wouldn't want to disappoint your parents, would you?"

4. I'm OK, You're NOT OK, They're NOT OK (Self-righteous critic)

Parental Attitude:	Workers' Attitude:
A typical statement from this position might sound like: "Well, it never fails! We just get settled in one program, and they decide to change it, or bring in someone new. No wonder Bobby can't learn. Of course, he's always been high strung -- ever since I first picked him up. Even having normal children is hard. I should know, I've got three of them, too."	In this stance, there is blame on both the child and the parent -- the child for not applying himself, the parents for not trying harder. The worker might think: "This kid is beyond help, and it's no wonder when you look at his parents."

5. I'm NOT OK, You're OK, They're OK (Melancholy)

Parental Attitude:

Here the parents blame themselves for the problems of their child, who they view with pity alternating with over-exaggerated pride at what he can accomplish. "Oh, if only I hadn't gone to that dance -- I knew there had been measles, but I didn't think . . . and now, our poor son. Thank heaven for that doctor, he's done wonders."

Workers' Attitude:

A rare position among workers; however, it may manifest itself when the worker feels inadquate in either his/her diagnosis or treatment, and when he/she does do something well, it often is chocked up to luck. This worker usually furthers his/her position by not keeping up with professional journals, or attending workshops, etc.

6. I'm NOT OK, You're OK, They're NOT OK (Servility)

Parental Attitude:

In this position, the parents suffer guilt for having given birth or having cause their child's handicap, and blame the workers for not setting everything right. They may feel toward the child: "We suffer, but you appreciate what we do, not like those people at the clinic." This person may keep the child at home to assuage his guilt even when the child would be better off in an institution.

Workers' Attitude:

This worker emphasizes his own inadequacies and those of the parents, viewing the child solely as a victim of circumstances (usually which the parent could have prevented). This worker may recommend institutionalization because of his negative view of the parents and his own ability to work individually with the child.

7. I'm NOT OK, You're NOT OK, They're OK (Servile Envy)

Parental Attitude:

Here, the parents may view the worker as a god, but are so envious of the worker's ability to relate to the child, that they often act from a position of disguised resentment. "Well, I try to work with him, but he's so slow that I just can't do it very long. You're able to get him to respond because you're trained to do it, but when you leave he just goes back to his old ways." Often the parents are ashamed of the child's condition.

Workers' Attitude:

An infrequent stance among workers, but may emerge toward children with disruptive behavior as in a classroom. "Well, there's nothing I can do with you; your poor parents, what they must go through, and look how hard they've tried!"

8. I'm NOT OK, You're NOT OK, They're NOT OK (Cynical)

Parental Attitude:	Workers' Attitude:
A position of futility and hopelessness pervades the attitude of this parent, who may give up and abandon the child to the least costly, least demanding and far-distant institution, or may keep the child as a reminder of their own inadequacy, but not providing adequate care.	Again a rare position, but may be evidenced with the internal rationalization: "Well, the child might be all right if the parents or I could get through to him, but this institution won't let me, and the parents resist, and the child hasn't much potential anyway."

It is apparent that the variety of potential positions is specifically greater among parents than with special education workers. This may be due to the fact of their differing circumstances. The worker most frequently has a choice in his/her profession. Most people do not go into or do not remain in the helping professions unless they have empathy toward their clients. Parents of exceptional children, on the other hand, have no choice in the matter. They are almost literally handed a child with a special condition. In such stressful situations, the parents' basic sense of acceptance toward self and others is immediately revealed, and there is no real opportunity for them to make the child different than he is.

In his book, "Parental Attitudes Toward Exceptional Children," Love (1970) has cited the work of V.S. Sommers who has identified five distinctive categories of parents toward children with impaired vision. These five seem also to be the ones most frequently encountered by special education workers, regardless of the handicap. They are listed below with the existential reference listed in parenthesis:

Acceptance (I, the parent, am OK; the Child is OK; the Worker is OK)

The parent has accepted the handicap in an objective way and shows genuine devotion and high evaluation of the child. No apparent guilt feelings or rebellion against the handicap are expressed.

Denial Reaction (the Parent is OK; the Child is OK; the Worker is NOT OK)

It is denied that the handicap has an emotional effect on the parent and that the child is actually handicapped. Educational plans for the child indicates that the parent does not accept any limitations for the child.

Overprotectiveness (the Parent is OK; the Child is NOT OK; the Worker is OK)

Parents are overwhelmed by a feeling of pity which expresses itself in oversolicitous and overprotective handling of the child.

Disguised Rejection (the Parent is NOT OK; the Child is NOT OK; the Worker is OK)

The handicap is considered a disgrace. The negative attitude and resentment toward the child is concealed by oversolicitous and anxious concern about his welfare and by an exaggeration of the duty of being good parents.

Overt Rejection (the Parent is OK; the Child is NOT OK; the Worker is NOT OK)

The child is openly resented, and the parent is aware of hostile feelings but builds up defenses to justify them. Society, the doctor, or teachers are blamed for their prejudice toward the handicap. By the process of projection, the parent achieves a feeling of self-justification for her own hostility and a relief from intense feelings of guilt.

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This material was researched and prepared with the assistance of Peter Simpson under the Office of Child Development's consultant contract with Roy Littlejohn Associates, Inc.

HELPING PARENTS TO HELP CHILDREN
An Existential View of Parental Attitudes Toward Their Handicapped Children, and of Professionals Toward Them

Part II: Exercise in the Identification of Parental Attitudes

Presented as a workshop to the
Annual Conference of the
Council for Exceptional Children

April 6, 1976
Chicago, Illinois

Presented by

Joseph Lapides, EdS
Director of Mental Health Services
Office of Child Development
Office of Human Development
Department of Health, Education & Welfare

Exercise in the Identification of Parental Attitudes

There follows five monologues extracted from the presenter's experience as a school psychologist and handicapped services specialist. At the end of each monologue, identify which of Sommers' categories -- acceptance, denial reaction, overprotectiveness, disguised rejection and overt rejection -- is being described:

MONOLOGUE NO. 1

Background: This monologue involves the father of an 11-year-old educably-retarded boy. Although he is eleven, the boy is in the fourth grade and has a second grade level reading capacity. The child is capable of rote memorization, but his ability to apply mathematical principles is severely limited. Because of his advanced age, he has become a disruption in the classroom. The teacher referred him to the school psychologist, who, after extensive testing and examination, found him to be retarded. The school psychologist is relaying this information to the father.

Father: (sitting rigidly) "But he knows the batting average of every player on Yankees and the Giants! How can he be retarded? If he can learn all those figures, how come he can't learn the material in school? It must be something you're doing. It can't be, it just can't be. You're picking on the kid because I'm Italian."

This monologue represents which of the following categories:

__ Acceptance
__ Denial Reaction
__ Overprotectiveness
__ Disguised Rejection
__ Overt Rejection

MONOLOGUE NO. 2

Background: The parents of a four-year-old child, Johnny, who has Downs Syndrome, have moved to a new community and are seeking professional assistance. The mother is speaking in response to the special education worker's question: "Tell me about your son."

Mother: "Johnny has Downs Syndrome. He's four years old and is a very cute little fellow. We like having him at home very much. He says 'Daddy' and 'Mommie' and he calls his big brother 'Butch.' As soon as the doctor discovered his condition . . ah . . . the doctor brought the baby to me and I noticed he didn't look quite right, and the doctor explained his suspicions. When we took him home, we entered him in a program for infant stimulation. Ever since we've all been working with Johnny, including his older sister -- she's eight, and even 'Butch,' who's only two years older. Now he can take care of himself quite well. He's toilet trained, he can dress himself. A psychologist has found that he functions at a 2½-year level. We've had our hard times. Sometimes we feel down and seem not to be making any progress, but we keep on working. He has his limitations, but he does what he can and we help him to provide the rest. When we moved to this area just a couple of weeks ago, the pediatrician suggested that we have him institutionalized -- I guess he was old-fashioned. I explained to him that that wasn't being done as much as it used to, and that we though we could -- with guidance -- provide for him better at home. That's when I called you."

This monologue represents which of the following categories:

__ Acceptance
__ Denial Reaction
__ Overprotectiveness
__ Disguised Rejection
__ Overt Rejection

MONOLOGUE NO. 3

Background: This fourteen-year-old child articulates fairly well, that is, his speech can be understood and he can make his basic needs known clearly. However, he suffers from echolelia and repeats phrases over and over. He plays with a string which he waves in front of his eyes. When he is required, he can add and subtract, but at a second and third-grade level, and he can read only basic functional words. Recently, he began to masturbate extensively.

Father: "The doctors are no good. They don't know what to do. They keep mis-diagnosing him. First, he was autistic, then he had brain damage, then mental retardation. That makes placement difficult. At first we followed the retarded notion and we placed him, but he was superior to everyone else, so that wasn't right. Then, we tried a school for the emotionally disturbed, but he didn't do well academically and he learned some new bad behaviors . . . and I think the one that he's got now. That's got to stop. This has all been very expensive. All our friends have houses but we live in this dinky apartment and our standard of living is way below some of the people who work for me! And that income hearing! That was degrading, and the judge just didn't understand. I'll bet he'd feel differently if he had a child like ours. He's a burden. We have to come here every other weekend; we can't go out when he is at home. The state simply doesn't provide enough facilities and services. And what are you going to do about his masturbating? That has got to stop. He needs to be punished."

This monologue represents which of the following categories:

__ Acceptance
__ Denial Reaction
__ Overprotectiveness
__ Disguised Rejection
__ Overt Rejection

MONOLOGUE NO. 4

Background: This situation involves a deaf child who has been institutionalized since he was three -- he is now 13. He has relatively good speech and is able to understand others. The school has recommended mainstreaming the child into a junior high school in the community where his parents lives. The following is the mother's response:

Mother: "That is going to be very difficult. For the past seven years that David has been here at the school, we simply haven't had a house big enough to hold him. You know, we moved into a smaller place after he'd been here three years. All his friends are here, and he hasn't been home very much because, as you know, we send him to that special camp every summer, so our house is just not geared for his needs. We entertain a lot -- you know how prominent my husband is -- and his speech is not really very good. He still talks funny and that would be awkward for our guests, and for David, too. You've done such a good job, and we've tried to be good parents; I mean, we send him to the best camps, and we got him that very expensive hearing aid, and we have donated a lot of money to the school and we visit on the special days you have organized. I just don't think it will work, and think of what he would miss here."

This monologue represents which of the following categories:

__ Acceptance
__ Denial Reaction
__ Overprotectiveness
__ Disguised Rejection
__ Overt Rejection

MONOLOGUE NO. 5

Background: This situation involves a five-year-old child with a cardiac condition. Enrolled in a Head Start program, the child is highly disruptive in the class, she hits other children, grabs their toys, won't participate in group activities, thus creating a serious classroom management problem. The parents have cautioned the school not to discipline her because of her heart problem. The teacher, at her witt's end, has called the mother in to determine what to do next.

Mother: "She's such a poor little thing. You know, you just can't permit any kind of strain on her. We've given her everything she needs, everything she wants. I just fear that some day . . . .

It's not good to discipline her. You know, I won't let her run around (and if you see her doing it, I know that you'll stop her). We try to keep her in her wheel chair as much as possible, and we carry her when she gets tired of that. I'm scared of setting limits on her, 'cause when I have tried it, she get's upset, and maybe she'll have an attack and . . . ."

This material was prepared with the assistance of Peter Simpson under the Office of Child Development's consultant contract with Roy Littlejohn Associates, Inc.

HELPING PARENTS TO HELP CHILDREN

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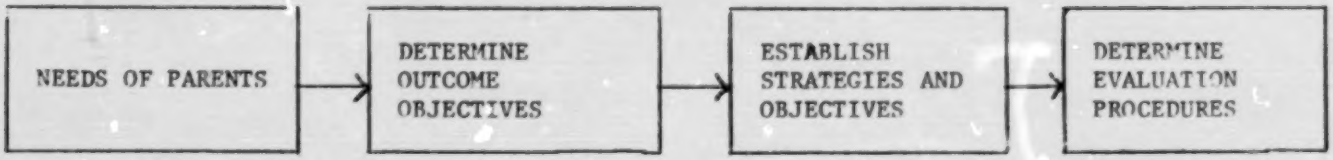
PLANNING YOUR PARENT PROGRAM

by David L. Lillie

STAGES IN PLANNING PARENT PROGRAMS



PLANNING PARENT PROGRAMS

PROGRAM AREA	GOALS	OBJECTIVES	ACTIVITIES	EVALUATION
SOCIAL AND EMOTIONAL SUPPORT	What emotional support do parents need?	What changes do I want to occur by the end of the year?	What are the best ways to achieve these objectives?	How successful was I in meeting the objectives?
INFORMATION EXCHANGE	Whac information do the parents & the center staff need from each other?	What information do I want known & by whom at the end of the year?	What are the best ways to provide that information?	How successful was I in meeting the objectives?
PARENT PARTICIPATION	What are the parents' needs to improve their interaction with their children?	What interaction & with what consistency do I want to occur by the end of the year?	What are the best ways to assure that these interactions take place?	How successful was I in meeting the objectives?
PARENT/ CHILD INTERACTION	What are the parents and centers' needs for participation?	What participation is to take place by the end of the year?	What are the best ways to achieve the objectives?	How successful was I in meeting the objectives?

Taken from "Parent Programs In Child Development Centers," Edited by David L. Lillie, University of North Carolina, Chapel Hill, 1972

PLANNING PARENT PROGRAMS

TARGET: Parents

GOAL: Involvement of parents in partnership arrangements stressing the needs, strengths, concerns and special knowledge the parents have and utilizing the expertise of the professional.

OBJECTIVES	ACTIVITIES	EVALUATION PLAN
To reduce anxiety by the end of the second year of the project in 90% of the parents.	Parent group discussions in which parents discuss their efforts to help their child on the problems they have encountered in such effort. A social worker will be assigned and will be available to each parent two hours a week for individual counseling.	Records will be kep listing parents who participate and their time of involvement. Anxiety levels will be measured by a scale (the IPAT 8-Parallel Form Anxiety Battery) as the parents enter the program and at the end of the second year.
To increase in 80% of the parents an understanding of the programs' objectives and strategies for their children six months after their child is enrolled.	One week after the child is accepted a family conference will be held at which time the program objectives and strategies will be explained. Written reports of child's progress will be sent monthly to parents. Parents report the child's home progress to the staff in individual monthly conferences.	The Parent Program Evaluator will develop an instrument which will measure the parents' understanding of the strategies and objectives of their child's program. Each parent will respond to that instrument six months after their child enters the program either in writing or in a parent interview or both.
To increase the effectiveness of the parents as teachers of their children using home made toys.	Home Visitor visits child's home weekly to demonstrate to parents how simply toys can be made in the home. During the visits parents learn to utilize toys as learning tools.	An anecdotal record is kept of each home visit. Parent keeps record of use of toys during the week. Video tapes of parent-child interaction are made weekly in the home and critiqued.
To establish & implement procedures that enable parents to give feedback to the project regarding their child's individual needs and the program in general.	A parent-feedback box will be installed at entrance to the center. The parent group will elect 2 representatives to the advisory council.	Parent coordinator checks parent-feedback box weekly. Two parent representatives serve on the Advisory Council.

WHERE PSYCHOLOGISTS FAIL WITH PARENTS

Ralph F. Blanco
Temple University

Presented at the Eighth Annual Convention of the National Association of School Psychologists, March 23-27, 1976, Kansas City, Missouri

Psychologists fail when they --

1. undertake cases too difficult and too complex for their training and personal stamina and are embarrassed to call for consultation.

2. When they seek to do less than is necessary to understand all the relevant problems and resolve the case in question.

3. seek to determine what the principal feels should happen to the child and obediently turn the case in that direction.

4. only attend to the problem noted on the referral form.

5. do no preparation for the parent feed-back and instead 'play it by ear.'

6. do not provide a longitudinal study of their child (except in cases involving brief behavior modification programs).

7. have but on theoretical frame of reference for understanding and treatment.

8. give parents "lectures" when no interest has been expressed, usually as a way of hiding from uncomfortable moments, and do not sufficiently lower their language level.

9. typical recommendations are only "psychotherapy and special education placement.

10. deal in generalizations in the psychological reports and especially in parent counseling.

11. avoid seeing parents for feed-back conferences and assign some lesser trained person to handle diagnostic and prescriptive work.

12. feel that the case is over after a diagnosis is made.

13. do not consider the teacher's personality, values, pressures and her anxiety about a particular child.

14. neglect to ask the parents about their feelings, values, attitudes, differences as they listen to feed-back.

15. are objective with parents by being emotionally neutral and aloof rather than human.

Psychologists fail when they --

16. fail to effect change at home because they do not know what to do to enhance its development.

17. allow too little time with parents in feed-back for comprehensive interpretation and discussion of prescriptions.

18. do not share test findings graphically with parents and offer copies for their permanent possession.

19. recommend that non-retarded children be placed in classes for the retarded.

20. forget how to say "no" to authority persons at crucial moments on professional decisions.

21. do not tell parents what they have done correctly with their child.

22. give parents feed-back in a test-by-test manner.

23. permit their personal lives and problems to enter into the discussion with parents.

24. interpret the parents' negative reactions to inquiries and diagnoses as personal attacks on their own judgment.

25. do not explore an extensive range of solutions and prescriptions with the parents.

MATCHING FAMILIES AND SERVICES

drawn from an article by Merle B. Karnes and R. Redi Zehrback, Exceptional Children, Volume 4, Number 8, May, 1975

A systematic approach to parent involvement. Assumptions of the model: a) staff should adopt a positive developmental view of children and their families; b) parents should be involved at the decision-making level; c) parents should have access to viable alternatives when they involve themselves; d) staff working with parents should view their role as consultative

STAGE	FUNCTION	SAMPLE ACTIVITIES
1	A careful total assessment is made of the child's actual functioning in such critical areas as social-emtional, physical cognitive, language and intellectural	Describe functional level of child: a. is able to hear 60 db sounds or louder b. speaks in one-word sentences c. responds to familiar faces d. runs, walks
2	Assessment continued by establishing specific goals and objectives based on estimates of the child's potential	Define potential goals and objectives: a. improved hearing with aid b. speak in two-word sentences c. play at parallel play level d. 1. experience grocery store 2. experience bus ride e. learn to swim
3	Descrepancies between where child is and where he is capable of being are carefully scrutinized to determine unmet needs	Determine Unmet Needs (difference between 1 & 2) a. hearing aid b. language stimulation c. socialization in groups d. broadening travel experiences e. train in swimming
4	Determine what the home is capable of providing <u>without</u> the <u>intervention</u> of other than simple suggestions or recommendations. Considerations -- <u>administrative</u>: costs, time, space, transportation; <u>family</u>: cultural, intellectual, knowledge, skills, attitudes; <u>child</u>: social, phsycial, motoric, intellectual, cultural.	Identify family capabilities: a. provide hearing aid b. limited ability c. limited ability d. not able to provide e. not now

STAGE	FUNCTION	SAMPLE ACTIVITIES
5	Determine the difference between the child's unmet needs and what family is able to provide.	Difference between Child's Needs & Parent's Abilities: a. (met) b. same as Stage 3, Item b. c. same as 3 c d. same as 3 d e. same as 3 e
6	Agency staff knowledgable about wide variety of programs. An entry level item designed to indicate that some person or agency must have a broad background of knowledge of alternative programs for involving parents.	Agency staff assessment of program availability: In preparation for selecting alternatives, list of all possible alternatives is required.
7	Agency/liaison workder develops list of alternative goals/programs. Knowledge gained from Stage 6 used to idetnify appropriate alternatives for meeting child's needs.	Alternative goals and programs: a. (met) b.1. parent training program (Karnes) 2. language-based pre-school program c. pre-school d.1. parent program "enhancing travel experience" 2. pre-school 3. student volunteer e. winter swimming program
8	Family members choose among the alternatives presented by the liaison worker, selecting the one(s) that they wish to follow to reach the child's unmet needs.	Family chooses alternative: a. (met) b.1. yes 2. yes c. yes d.1. no 2. yes 3. yes e. later

STAGE	FUNCTION	SAMPLE ACTIVITIES
9	Determine difference between child's needs and what family agrees to provide.	All plans agreed to except: d.1. attend parent program on "enhancing travel experience" and e. delay entrance into swimming program.
10	Agencies involved with the family assess their capabilities and responsibilities and decide whether or not they are willing and able to work with the parents toward the parents' selected goals. Agencies decide whether they will work with the child toward the same goal and/or provide the child with additional services available to or through the parents	Agencies determine to 1) work with the parents toward their choices and/or 2) choose to work with the child in some other area(s): a. (met) b.1. agree to enroll in Karnes course, based on parent program. 2. enroll in language-based program. c. same as b.2. d.1. no action; put on need list 2. same as b.2. 3. no volunteer available; put on wait list e. put on wait list
11A	Chosen plans are implemented	Continue action toward selected goals: a. (met) b.1. Parent started program 3-1-76 2. Child started program 3-15-76 c. same as b.2 d.2. same as b.2
11B	Continuous evaluations and reassessments are conducted at pre-planned intervals with new planned actions established when progress is made toward needs that have been given prime attention	Reassess at stated intervals and replan, adding unmet needs: a. (met) b.1. review program at 6 week intervals b.2., c., d.2 } interval evaluation and 9-week interim review and yearly total review

STAGE	FUNCTION	SAMPLE ACTIVITIES
11C	Records are maintained of the unplanned-for unmet needs. Records must be continually reviewed as progress is made toward the higher priority needs so that provisions for unmet needs can be added to plan when resources and time permit.	Unmet needs and unplanned needs remain until resolved or added to plan: d.1. No action. Review need and possibly reschedule parents into "enhancing travel" program in three months. 3. Put on waiting list for volunteers. e. schedule for summer swimming lessons.

WHAT DO PARENTS OF RETARDED PEOPLE WANT FROM A CLINIC*

by Mora Skelton, M.S.W.

1. Tell us the Nature of our Problem as soon as Possible

It is not easy to inform parents that their child is retarded. It is not easy for parents to absorb this kind of information, especially those for whom the idea is new. Several parents said frankly that when the diagnosis was first given them, the physician may have continued to elaborate, but that they (the parents) were too upset to be able to grasp what he was saying. (It has been) recommended that every interpretation interview to new parents be followed by a second of a very similar nature, to make sure that the information was understood, and to reply to questions which may have occurred to the parents in the meantime.

2. Always Try to See Both Parents

An upset mother should not have to try to interpret the clinic findings to her husband, whose perception of the problem may be different from hers, and whose questions may be different from those she has asked. The trend is to include brothers and sisters in the clinic interpretation and, whenever appropriate, the retarded person himself. Fathers asked that the clinic bear in mind that the breadwinner is taking time off from work and make an effort to see the family on time, and to avoid cancellation of appointments after the family has arrived -- often from a distance.

3. Watch Your Language

Most parents appreciate plain speaking, without resort to medical, social work, or psychological jargon. Unfamiliar language contributes to the parents' sense that they have not been "told anything." They cannot be expected to relate to or retain material which they have not really understood.

4. Help Us to See That This Is Our Problem

Most parents know very well that the problem is theirs, and they want to see their role in helping a retarded family member. Whenever possible visits to the clinic should be seen as the establishment of a partnership between a family who have a handicapped member and a professional team who have some of the know-how required to help them.

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* -- excerpted from an article appearing in Canada's Mental Health, March/April 1973, p. 23-28 (CEC Microfiche Reference Number: EC 05 1618)

5. Help Us to Understand Our Problem

A diagnostic assessment is not enough. To be of use to the parents, the diagnosis must be understood, and should lead to some form of treatment or management plan.

6. Know Your Resources

It is difficult to raise a normal child. The family with a retarded member needs the relief from realistic burdens which referral to an appropriate community resource can bring. Clinics should be fully aware of the availability in their area of special nursery schools, day care services, schools for the retarded, sheltered workshops, community residences, camps, parent association groups and government facilities. Referrals to other agencies should be facilitated and followed up by the clinic to make sure that they are appropriate, and that the service is, in fact, given.

7. Never Put Us on the Defensive

All parents make mistakes. Parents of the retarded have sometimes pressed their child too hard, or have over-protected him. They sometimes become defensive -- and people on the defensive find it hard to ask for help, or to use it constructively. It would appear that there is always the danger that parents will develop negative feelings toward clinic personnel who are giving them bad news, without being able to offer them a real solution. Parents are quick to sense if they are being talked down to, put off, or -- as one parent put it -- pacified.

8. Remember That Parents of Retarded Children are Just People

Families with a retarded member were not chosen for their difficult role on the basis of strength of mind or character. They are usually seen at a clinic at a time of strain, discouragement, and hypersensitivity. Some degree of stress is inevitable and may be part of a process of adjustment to the problem.

9. Remember That We Are Parents, and That You Are Professionals

A number of major and minor complaints were made by the parents consulted. One of them spoke of repeated telephone calls which were not returned -- a problem not unheard of in professional circles -- but one with which it is difficult for a distressed parent to cope. Other problems included long waits at clinic after the appointment time; lack of provision for patient or family who can't get home or to a restaurant for a meal; scheduling of a parent conference for 9:30 a.m. when the family must come 200 miles, or stay overnight; lack of encouragement to return to

the clinic at a later date, when time brings new problems; lack of contact with other than very junior members of staff; and loss of social worker or other team member without notification or replacement of the staff member.

10. Remember the Importance of Your Attitude to Us

Objectivity in assessing the problem is necessary and good, but parents need to sense an underlying empathy on the part of the clinic team. Parents need to feel respect and interest, to "be treated like human beings," as one father said. They need to feel that their retarded family member is also respected. It gives them courage, and a sense that they have found an ally in their effort to help the retarded person reach his full potential, and to find a place in society.